
Cost of Treating Birth Defects in State Crippled Children's Services, 1975

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GOVERNMENT IS NOW the primary bill-payer for health. The national health bill increased from \$12 billion in 1950 to more than \$139 billion in 1976, rising from 4.5 percent of the gross national product to 8.6 percent. Some 40 percent of the nation's health care costs were paid by the Government, 33 percent by patients directly, and 26 percent by private health insurance (1). Medical care has cost the taxpayers more and more in recent years.

This paper is an attempt to answer the question, "What is the cost of treating birth defects and how many birth defect patients receive medical care through publicly funded programs?" Since there is no single data source for measuring the total inpatient and outpatient costs defrayed by different medical resources, one can only estimate based on a few existing data sources.

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Material and Methods

The federally aided State Crippled Children's Services is one of the nation's most extensive medical care programs that provides care primarily for children under 21 years whose parents cannot pay for private care. Information regarding the number of children and their age, race, residence, and specified services received under this program are published and made available for public use by the Health Services Administration, Bureau of Community Health Services. The specified conditions for which the children are treated have been assigned International Classification of Diseases, Adapted 8th revision codes; total costs, including physicians' fees, inpatient and outpatient hospital care, home care, and other ancillary services are available for analysis from the Crippled Children's Services, Michigan Department of Public Health (2). Therefore, the average costs in Michigan for treating specified birth defects can be used as a base to estimate total costs of treating birth defects for each State. Medical costs vary from region to region in the United States, and therefore the estimated medical costs for individual States are derived from data based on the Michigan costs and adjusted for better regional representation.

In 1976, the average comparative indices for medical care for 39 U.S. metropolitan areas were available from the Bureau of Labor Statistics (3). The indices

can be standardized by the direct method which treats the Michigan index as 100. With the adjusted medical indices, the estimated medical costs of treatment under Crippled Children's Services for specified States can be derived as follows :

$$\begin{array}{l} \text{Number of birth} \\ \text{defects treated} \\ \text{under the} \\ \text{specific State's} \\ \text{program} \end{array} \times \begin{array}{l} \text{average costs of} \\ \text{Michigan program} \end{array} \times \begin{array}{l} \text{adjusted compar-} \\ \text{ative medical} \\ \text{cost index for} \\ \text{specified State} \end{array}$$

= the total estimated costs for treating birth defects specified by State.

The estimated costs for treating birth defects by State are presented in table 1.

Findings

In 1975, 523,225 U.S. children under age 21 were treated under the State Crippled Children's Services; 54 percent were males and 46 percent were females. Among these children, 59 percent were white and nearly 35 percent were nonwhite; no information was available on race for 7 percent. Some 14.4 per 1,000 nonwhite and 4.7 per 1,000 white children under 21 were treated for birth defects under the Crippled Children's Services. The nonwhite utilization rate was three times that of the white children. Nearly 1 of 3 children were under

6 years old; 28 percent were 5-9; 24 percent were 10-14; and 17 percent of the children were 15 and over. Most of these children (85 percent) received treatment at outpatient clinics. More than one-half of the new patients were under 5 years old. Therefore, these programs are a good source for diagnosing or identifying part of the late-onset birth defects among newborns (table 2).

Among the 523,225 children served under the Crippled Children's Services, nearly 23 percent were treated for more than 1 condition. Birth defects, the most common of all disorders, reportedly accounted for nearly 30 percent of all treated conditions. Diseases of the nervous system and sense organs and diseases of the bones and organs of movement accounted for 40 percent of all treated conditions (table 3).

It can be estimated that birth defects treated under the Crippled Children's Services cost the taxpayers more than \$160 million each year. The breakdown of this cost by State, presented in table 1, includes expenses of physicians' services, inpatient and outpatient hospital care, home care, appliances, and ancillary services provided under this program. Some of the children who were treated under the Crippled Children's Services had some other forms of insurance coverage. When children who had other forms of coverage were ad-

Table 1. Number of birth defects treated and estimated annual expenditures by State, Crippled Children's Services, 1975

State	Number of birth defects treated ¹	Annual expenditures ²
Total	198,448	\$160,059,000
Alabama	4,525	2,613,000
Alaska	510	735,000
Arizona	3,628	2,229,000
Arkansas	2,800	1,936,000
California	12,722	15,540,000
Colorado	1,096	901,000
Connecticut	1,585	1,715,000
Delaware	2,466	1,460,000
District of Columbia	822	662,000
Florida	13,606	12,467,000
Georgia	7,683	5,903,000
Hawaii	991	1,082,000
Idaho	991	852,000
Illinois	8,460	7,184,000
Indiana	3,702	3,313,000
Iowa	5,438	5,593,000
Kansas	3,372	2,198,000
Kentucky	6,362	3,622,000
Louisiana	4,649	3,015,000
Maine	1,044	824,000
Maryland	2,514	1,564,000
Massachusetts	3,222	2,239,000
Michigan	4,168	3,790,000
Minnesota	4,271	3,131,000
Mississippi	2,820	1,667,000
Missouri	4,991	3,416,000
Montana	396	271,000
Nebraska	2,081	1,662,000
Nevada	775	655,000
New Hampshire	1,200	1,199,000
New Jersey	2,470	2,366,000
New Mexico	1,674	1,191,000
New York	11,724	8,094,000
North Carolina	8,270	5,297,000
North Dakota	558	369,000
Ohio	6,148	5,597,000
Oklahoma	207	201,000
Oregon	4,272	5,124,000
Pennsylvania	11,816	6,697,000
Rhode Island	619	565,000
South Carolina	4,431	3,637,000
South Dakota	1,575	622,000
Tennessee	5,662	4,096,000
Texas	7,455	7,886,000
Utah	1,087	865,000
Vermont	1,265	775,000
Virginia	7,514	6,316,000
Washington	1,720	1,434,000
West Virginia	4,740	4,031,000
Wisconsin	1,668	910,000
Wyoming	683	548,000

¹ Some children are treated for more than 1 birth defect; hence these figures overestimate the total number of children affected by birth defects.

² Estimates for States based on cost data from Michigan Crippled Children's Services, adjusted to reflect regional variations in medical costs, as estimated by the Bureau of Labor Statistics. This includes expenditures for physicians' services, inpatient and outpatient hospital care, home care, appliances, and ancillary services.

Table 2. Selected demographic information on children treated, Crippled Children's Services, 1975

Characteristic	Number	Percent
Sex:		
Male	284,136	54.3
Female	238,495	45.6
Not reported	594	0.1
Total	523,225	100.0
Race:		
White	306,880	58.7
Nonwhite	181,082	34.6
Not reported	35,263	6.7
Total	523,225	100.0
Age:		
< 1	20,839	4.0
1-4	140,531	26.9
5-9	146,766	28.0
10-14	122,907	23.5
15 and over	89,336	17.1
Not reported	2,846	0.5
Total	523,225	100.0

Table 3. Number and percent of conditions treated, by diagnostic category, Crippled Children's Services, 1975

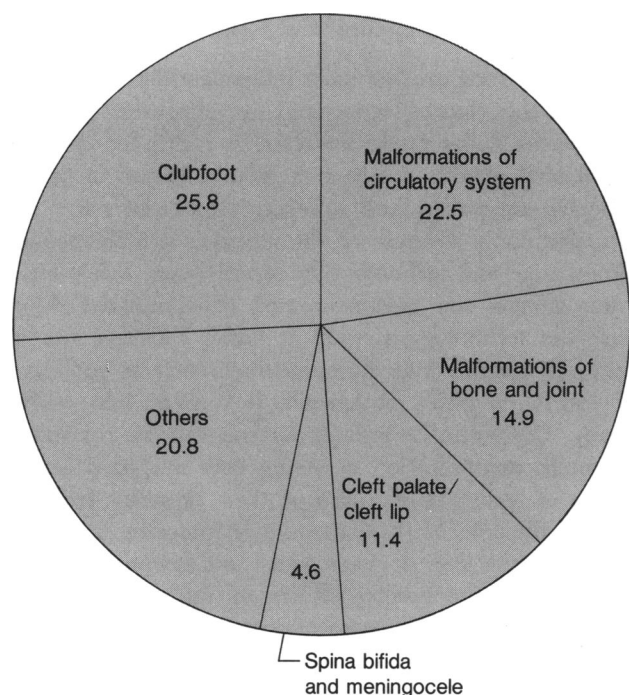
Diagnosis	Conditions treated ¹	
	Number	Percent
Birth defects	198,448	29.4
Other diagnoses ² :		
Diseases of nervous system and sense organs	173,499	25.7
Diseases of the bones and organs of movement	96,539	14.3
Mental, psychoneurotic, and personality disorders	28,705	4.3
Accidents, poisonings, and violence	25,008	3.7
Diseases of the digestive system	16,793	2.5
Diseases of the circulatory system	15,383	2.3
Diseases of the respiratory system	9,483	1.4
Allergic, endocrine system, metabolic, and nutritional diseases	8,835	1.3
Neoplasms	8,506	1.3
Diseases of the genitourinary system	8,212	1.2
Infective and parasitic diseases	6,433	1.0
Other diseases of early infancy	5,610	0.8
Diseases of the skin and cellular tissue	3,539	0.5
Diseases of blood and blood-forming organs	3,008	0.5
Birth injuries	2,230	0.3
Examinations and other ill-defined conditions ³	63,737	9.5
Total	673,968	100.0

¹ Some children are treated for more than 1 condition; hence these figures overestimate the number of children treated for 1 or more conditions (523,225).

² Some "other diagnoses" include conditions regarded as birth defects. These cases have been deleted from "other diagnoses" and added to "birth defects."

³ Includes examinations made, no abnormality reported; provisional or deferred diagnoses; and other ill-defined conditions.

Percentage distribution of total birth defects treated, by specified conditions, Crippled Children's Services, United States, 1975



Others:

Unspecified malformations	15.9	Diabetes mellitus	0.7
Cystic fibrosis	2.3	Sickle cell anemia	0.6
Mongolism	1.0	Phenylketonuria	0.3

mitted to the hospital for any major procedure, the hospital bills were sent to the insurance company; Crippled Children's Services or Medicaid made up the difference beyond what the insurance company paid. The estimated costs presented here include some costs

defrayed by sources other than Crippled Children's Services. Complete data on the costs defrayed by other Government programs such as Medicaid and by insurance and other private sources are not available.

About 51,000 cases of clubfoot were treated at a cost of \$11 million. Treatment for nearly 45,000 cases of malformations of the circulatory system cost more than \$68 million. Together, these two diagnostic groups accounted for one-half of all birth defects treated and for one-half the total cost of treating all congenital conditions (table 4 and chart).

Average annual cost of care per condition varied widely, from highs of \$1,760 for sickle cell anemia, \$1,000 for diabetes mellitus, and \$1,530 for circulatory malformations, to lows of \$210 for clubfoot and \$100 for phenylketonuria (PKU). An estimate of the number of children under 21 who were affected by these selected birth defects (4) and number of children under 21 who were treated by Crippled Children's Services are presented in table 5.

Discussion and Conclusions

Crippled Children's Services covered only an estimated 3.5 percent of the children affected by Down's syndrome, nearly 6 percent of sickle cell anemia, and some 14-17 percent of PKU, spina bifida, or malformations of the circulatory system. Therefore, the average costs for treating these conditions should be interpreted with caution. However, more than 32 percent of the children affected by clubfoot, 30 percent of cleft palate-cleft lip children, and 37 percent of cystic fibrosis children were treated under Crippled Children's Services in the United States.

Table 4. Number and percentage of birth defects treated, estimated annual expenditures, and average annual cost by specified birth defects, Crippled Children's Services, 1975

Diagnosis	Conditions treated		Annual expenditures		Average annual costs
	Number	Percent	Dollars	Percent	
Clubfoot	51,240	25.8	\$ 10,899,000	6.8	\$ 210
Malformations of circulatory system	44,614	22.5	68,067,000	42.5	1,530
Malformations of bone and joint	29,519	14.9	18,265,000	11.4	620
Cleft palate-cleft lip	22,691	11.4	10,174,000	6.4	450
Spina bifida and meningocele	9,156	4.6	11,458,000	7.2	1,250
Cystic fibrosis	4,655	2.3	3,530,000	2.2	760
Mongolism	1,930	1.0	1,431,000	0.9	740
Diabetes mellitus	1,420	0.7	1,427,000	0.9	1,000
Sickle cell anemia	1,195	0.6	2,104,000	1.3	1,760
Phenylketonuria	518	0.3	53,000	...	100
Other congenital malformations	31,510	15.9	32,651,000	20.4	1,040
Total	198,448	100.0	\$160,059,000	100.0	...

Table 5. Prevalence of selected birth defects and number and percent of birth defect children treated under Crippled Children's Services, 1975

<i>Birth defects</i>	<i>Estimate of children under 21 with condition currently</i>	<i>Number of children under 21 treated under Crippled Children's Services 1975</i>	<i>Percent</i>
Clubfoot	156,000	51,240	32.8
Malformations of circulatory system . .	260,000	44,614	17.2
Cleft palate or cleft lip	74,000	22,691	30.7
Spina bifida or hydrocephalus, or both . .	58,000	9,156	15.8
Cystic fibrosis	12,500	4,655	37.2
Mongolism	55,000	1,930	3.5
Sickle cell anemia . . .	20,000	1,195	6.0
Phenylketonuria	3,500	518	14.8

Birth defects were reported nationally only when fatal; therefore, incidence and prevalence figures can only be estimated, based on selected published birth defect studies. Prevalence figures by selected birth defects can be compared with the number of children treated under Crippled Children's Services in an effort to determine how the services are being used. However, statistics similar to those presented in table 5, by State or by other specified birth defects, could not be obtained for comparison.

The data presented summarize only one component of the costs incurred for treating birth defects under a Government-funded program. Costs of inpatient care and private physicians' office visits were not included in the analysis. Based on the 30 percent of U.S. hospital discharge records on file with the Commission on Professional Hospital Activities, Ann Arbor, Mich., in 1975, one can estimate that 1.2 million children and adults were hospitalized for treatment of birth defects at a cost of more than \$1 billion for hospital stay alone. Nearly 50 percent of these patients were under 20 years old. According to a report prepared by Ma, based on special tabulations from the Ambulatory Medical Care Survey, National Center for Health Statistics, 1976, 1 of 40 physician visits were for treatment of birth defects. More than 9.6 million of these visits were for the treatment of diabetes mellitus, nearly 3.2 million for structural malformations, and some 436,000 for the treatment of other metabolic or hereditary disorders. Of these visits, 17 percent of the patients were under 24 years old. In 1975, the estimated total costs for treating birth defects at private physicians' offices amounted to nearly \$200 million for services alone, assuming the

average charges were \$15 per patient per visit. To gather a more complete picture of the costs of treating birth defects, efforts had to be made to study indiscriminately the costs of inpatient care, outpatient care, specially funded programs, and institutionalized care.

Birth defects are the most serious child health problem in this country today and are expensive to treat. While the dollar figures involved in caring for children with birth defects can be compiled in statistical tables, the human sorrow and suffering that often result are immeasurable. Because of the advancement in medical knowledge and technology in recent years, a few birth defects now can be ameliorated or eliminated if we use the technology already at hand. Effective use of the Rh vaccine can eliminate birth defects produced by an Rh negative mother who delivers an Rh positive baby. Congenital rubella syndrome can be prevented through immunization of young boys and girls in the hope of reducing exposure of their pregnant mothers to the disease (5). Effective use of intensive care units can save the lives of many immature newborns as well as improve the quality of life of the survivors (6). Early and frequent prenatal care can prevent immaturity and low birthweight associated with perinatal damage to the brain and other organs of a newborn. Prenatal diagnostic procedures can identify selected birth defects early in pregnancy. In certain high-risk situations, it is already possible to diagnose and treat the affected unborn babies. Many birth defect victims can be treated to slow, stop, or partly reverse harmful effects. However, we can see clearly a new trend developing: the growing emphasis of preventive programs. We believe that a baby's best chance for a healthy beginning is to be born to a healthy mother in a healthy environment.

References

1. The cost of health [editorial]. *Health Values: Achieving High Level Wellness*. 1: 290-291, November-December 1977.
2. Michigan Department of Public Health: Statistical reports of division of services to crippled children. Lansing, Mich., 1973-74 and 1974-75.
3. Department of Labor, Bureau of Labor Statistics: Autumn 1976 urban family budgets and comparative indices for selected urban areas. Washington, D.C., Apr. 27, 1977.
4. The National Foundation-March of Dimes: Facts, 1978. White Plains, N.Y., 1977.
5. Stickle, G.: The health of mothers and babies: How do we stack up? *Fam Coordinator* 26: 205-211, July 1977.
6. Thompson, T., and Reynolds, J.: The results of intensive care therapy for neonates. I. Overall neonatal mortality rates. II. Neonatal mortality rates and long-term prognosis for low birthweight neonates. *J Perinat Med* 5: 59-75, May 1977.